



# Supporting Adults with Intellectual and Developmental Disabilities in their Communities

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## Introduction

### Individuals with intellectual and developmental disabilities (IDD) have told us they want:

- » **To be self-determined.** Adults with IDD describe self-determination as being able to say what they want or do not want, make their intentions heard, and make and act on decisions.<sup>1</sup>
- » **To work in the community.** Many studies have found that people with IDD want to work in the community. One study of individuals with IDD, their family, and support staff found that the majority of people would like employment outside sheltered workshops, or at least consider it an option. People surveyed also believe that adults with intellectual disabilities can perform outside workshops. The interest in working in the community was not associated with the severity of the disability.<sup>2</sup> In another study, individuals with IDD shared the reasons they want to work: (a) earnings, (b) productivity, (c) the admiration of others, and (d) the quality of social relationships.<sup>3</sup>

### Individuals with IDD have told us they need the following to accomplish their goals:

- » **Support and assistance.** This must be offered in a way that allows for individual choice. People with IDD have reported that it is difficult to be self-determined when others make decisions about where they work, where they live, and how they spend their money; when they fear that speaking out will lead to outcomes they do not want; when they state their goals and desires and support staff do not follow through; and when they do not have opportunities to make choices.<sup>4</sup>

- » **Encouragement.** Professionals in disability services appear to play a relatively minimal role in encouraging adults with IDD to pursue integrated employment. In some cases, professionals have even encouraged adults with IDD to choose sheltered workshops.<sup>5</sup> And family has been found to be a significant influence on individuals' decisions about work.<sup>6</sup>
- » **Opportunities.** Individuals with IDD have said that they want opportunities to do meaningful work, demonstrate their skills and talents, choose their own careers, and have the same opportunities for career advancement as people without disabilities.<sup>7</sup>
- » **Respect.** Individuals with disabilities expect to receive the same level of respect as those without disabilities.

### A few ways to help make these goals a reality:

#### 1. Support individuals to fully participate in the person-centered planning process.

- » Pre-plan with the individual to make sure he/she understands the meeting and is prepared to contribute.
- » Direct statements and questions to the individual, not others.
- » Speak at the individual's language level.
- » Use accommodations as needed.
- » Avoid jargon and patronizing language.
- » Do not refer to the individual as though they were not in the room or speak about them in the third person.
- » Write suggestions on flip charts, use good group brainstorming skills, and actively involve the individual in the group process.<sup>8</sup>

1 Nonnemacher, S. L., & Bambara, L.M. (2011). "I'm supposed to be in charge": Self-advocates' perspectives on their self-determination support deeds. *Intellectual and Developmental Disabilities*, 49(5), 327–340.

2 Migliore, A., Mank, D., Grossi, T., & Rogan, P. (2007). Integrated employment or sheltered workshops: Preferences of adults with intellectual disabilities, their families, and staff. *Journal of Vocational Rehabilitation*, 26, 5–19.

3 Timmons, J. C., Hall, A. C., Bose, J., Wolfe, A., & Winsor, J. (2011). Choosing employment: Factors that impact employment decisions for individuals with intellectual disability. *Intellectual and Developmental Disabilities*, 49(4), 285–299.

4 Nonnemacher, S. L., & Bambara, L.M. (2011). "I'm supposed to be in charge": Self-advocates' perspectives on their self-determination support deeds. *Intellectual and Developmental*

*tal Disabilities*, 49(5), 327–340.

5 Migliore, A., Grossi, T., Mank, D., & Rogan, P. (2008). Why do adults with intellectual disabilities work in sheltered workshops? *Journal of Vocational Rehabilitation*, 28, 29–40.

6 Timmons, et al. (2011).

7 Walker, A. (2011). Checkmate! A self-advocate's journey through the world of employment. *Intellectual and Developmental Disabilities*, 49(4), 310–312.

8 Whitney-Thomas, J., & Timmons, J. C. (1998). Building authentic visions: How to support the focus person in person centered planning. *Research to Practice Brief*, vol. 4, no. 3. Boston, MA: University of Massachusetts Boston, Institute for Community Inclusion.

## 2. Help each individual develop a life vision and long-term goals.

This includes allowing the individual to try out the range of options and experiences to encourage choice.<sup>9</sup>

## 3. Consider how you can change your behavior to

be approachable and accessible, listen without judgment, and support the individual to follow through with their goals.<sup>10</sup>

## 4. Help each individual identify the supports

they need to live the life they want. Search out supports that you don't know about yet. These supports should help the individual reach their goals. They should *not* be chosen because they make life easier for the support team.

## 5. Reframe your thinking about pre-vocational

services. Effective pre-vocational services are time-limited, are provided in community settings (not a segregated facility), have a connection to competitive employment, and are *not* necessary for every individual. Pre-vocational services, are delivered to further habilitation goals such as attendance, task completion, problem solving, interpersonal relations, and safety. They create a path to competitive employment. Individuals are compensated at or above the minimum wage, and do not receive lower wages or fewer benefits than people without disabilities performing similar work.<sup>11</sup>

## 6. Help individuals and family members face

their fears. When deciding about day services, some adults with IDD and their families have concerns about safety, transportation, long-term placement, work hours, disability benefits, social environment, and work skills issues.<sup>12</sup> These are important concerns, but should not block people from real life in the community.

## Day and Employment Services

There are four primary types of day and employment services for individuals served by state IDD agencies:

integrated employment services, community-based non-work services, facility-based work services, and facility-based non-work services.

Service choices affect individual opportunities and outcomes, and one service type is not a prerequisite for another.



Service	General Description
Integrated employment	Integrated employment services are provided in a community setting and involve paid employment of the participant. Includes competitive employment, individual supported employment, group supported employment, and self-employment supports.
Community-based non-work	Community-based non-work services support people with disabilities to access community activities. These services occur in settings where most people do not have disabilities, and do not involve paid employment of the participant. Activities include general community participation, volunteer experiences, or using community recreation and leisure resources. The majority of an individual's time is spent in the community. This service category is often referred to as community integration or community participation services.
Facility-based work	Facility-based work includes all employment services that occur in a setting where the majority of employees have a disability. Continuous job-related supports and supervision are provided to all workers. This service category is typically referred to as a sheltered workshop, work activity center, or extended employment program.

<sup>9</sup> Nonnemacher & Bambara. (2011).

<sup>10</sup> Nonnemacher & Bambara. (2011).

<sup>11</sup> Centers for Medicare and Medicaid, CMCS Informational Bulletin, September 16, 2011

<sup>12</sup> Migliore et al. (2008).

## Integrated Employment

Integrated employment services are provided in a community setting. These services help people with disabilities to obtain and maintain competitive employment, build a career, and become a valued member of the workforce.

Individual competitive integrated employment is the preferred outcome. The goal of individual integrated jobs is highlighted in Medicaid regulations and in the Workforce Innovation and Opportunity Act.

Ongoing supports may be included as an integrated employment service if they are needed for the individual to maintain their job. The individual's preferences, interests, and capacities drive the choice of the job and career.

### Main categories of integrated employment services

- » **Competitive, individual supported employment:** Working in an individual job, typically as an employee of a community business, where the majority of co-workers do not have disabilities. Wages are the same as those of non-disabled workers performing similar job tasks. Individual supported employment involves ongoing paid support of the employee with a disability, while competitive employment is a time-limited service that provides supports only during the job search and early stages of the job.
- » **Group supported employment:** Groups of individuals working in integrated job settings, typically as part of an enclave or work crew. In general, group supported employment applies only for group sizes of eight or fewer. These employees may or may not be paid the minimum wage. Compared to employees without disabilities, individuals engaged in this type of employment usually earn lower wages. They are also less likely to receive benefits.
- » **Self-employment:** Control or ownership of a small business by an individual with a disability. This does not include a business that is owned by an organization or provider.

### Common integrated employment services

- » Market-based job-related assessment (work experiences, situational assessments, internships, and job shadowing)

- » Discovery, a comprehensive process used to explore the individual's life to gain an understanding of the person's perspectives, interests and experiences
- » Employer outreach and negotiation
- » Career development
- » Job development
- » Job analysis
- » Job matching (the interests and abilities of the job seeker match those of the employer)
- » Job carving: Developing a new job description based on tasks derived from a single traditional job. The carved job description contains one or more, but not all, of the tasks from the original job description.
- » Job creation: Developing a new job description for a new position within the business, fully capitalizing on the skills and strengths of the employee.
- » Training and systematic instruction (purposeful and step-by-step instruction)
- » On-the-job and off-the-job coaching and support, including support through coworkers and supervisors
- » Referral to benefits training and analysis
- » Developing strategies to fade supports
- » Transportation planning
- » Coordination with residential providers
- » Supporting self-employment
- » Referral to assistive technology assessments and other job accommodation tactics

### Quality indicators for integrated employment services in your state

- » The hours worked are sufficient to meet the individual's wants and needs.
- » Wages are equal to those of employees without disabilities.
- » There are opportunities to earn paid time off, purchase health insurance, and participate in retirement plans.
- » There are opportunities for career advancement.
- » The individual participated in choosing their service provider and had adequate information to inform their choice.
- » The individual was given the choice to accept or decline the job. After spending time on the job, they can choose to resign or to continue employment.
- » The individual's work schedule corresponds to the employer's requirements and the individual's needs, rather than to service providers' schedules.

## Pre-Vocational Services

### Reframing pre-vocational services

Historically, pre-vocational services have been cast as a step in the integrated employment process, have occurred in sheltered workshops, and have paid less than minimum wage. Today, employment professionals recognize that pre-vocational services are not a prerequisite to employment and are optional, but when they are offered, they should be provided in the community as part of a direct and time-limited pathway to integrated employment.

Longitudinal data suggest that individuals do not typically move from sheltered work services to integrated employment. The National Disability Rights Network<sup>13</sup> has advocated against use of sheltered workshops and payment of sub-minimum wage to people with disabilities.

At the federal level, both the Rehabilitation Services Administration (RSA) and the Centers for Medicare & Medicaid Services (CMS) have refocused the intent of employment services towards integrated employment. In 2001, the RSA formally eliminated sheltered employment as a successful outcome for clients of state vocational rehabilitation agencies.

In 2011, the CMS<sup>14</sup> issued an informational bulletin to clarify the use of pre-vocational services that can be funded using Medicaid dollars. The bulletin stated that:

- » The optimal outcome for pre-vocational services is competitive, integrated employment in the community.
- » The individual is compensated at or above the minimum wage, but not less than the customary wage and level of benefits paid by the employer for the same or similar work performed by individuals without disabilities.
- » Services are expected to occur over a defined period of time, i.e., are not intended to be a long-term support.
- » Individuals receiving pre-vocational services must have employment goals in their person-centered services and supports plan.



- » Participation in pre-vocational services is not a pre-requisite for supported employment services funded under the waiver.

Several states are moving away from using pre-vocational services to support work and work preparation in a facility-based setting. Instead, they are using these services to support community-based training and work experience.

Examples of state efforts include:

- » Eliminating pre-vocational services for those entering the service system
- » Developing plans to transition those who have been in long-term pre-vocational services to integrated employment services
- » Improving the quality and outcomes of pre-vocational services. This includes revising service definitions and billable activities so that this service type is a defined, time-limited service, with the specific objective of supporting an integrated employment outcome.

Pre-vocational services can have merit if professionals creatively use the options available in their communities to inform individuals about the world of work. Examples include:

- » Volunteering at non-profit organizations
- » Career exploration
  - Touring businesses
  - Job shadowing
  - Informational interviews
- » Health and fitness
  - Participating in opportunities available in the broader community

<sup>13</sup> National Disability Rights Network. (2012). Beyond segregated and exploited: Update on the employment of people with disabilities. Washington, DC: Author.

<sup>14</sup> Centers for Medicare and Medicaid Services. Informational bulletin: Updates to the §1915(c) Waiver Instructions and Technical Guide regarding employment and employment related services: <http://1.usa.gov/1xHSbOF>



- » Job-seeking skills and strategies
  - Using local job centers, libraries
  - Engaging employers and their human resources staff to practice interviewing, writing job applications, and preparing a resume
- » Technical and community college courses
- » Financial management
  - Learning money skills by shopping in the community, opening a bank account, and developing a budget
- » Clubs, associations, leagues, and other community groups
  - These offer the chance to develop and pursue interests, to meet like-minded people, and to participate in activities in fully integrated community settings.

### Quality indicators for pre-vocational services in your state

Ask these questions to assess the likelihood that your state's pre-vocational services will lead to integrated employment:

- » Are individuals able to receive supported employment services even if they have not already received pre-vocational services?
- » Are pre-vocational services provided in community-based settings that allow job exploration and natural opportunities for skill development?
- » Do the services allow individuals to develop general, non-job-task-specific strengths and skills?
- » Are the majority of individuals in pre-vocational services transitioning to integrated employment?
- » Do the services support the individual to obtain a job in the community that matches their interests, strengths, priorities, and capabilities, while following federal wage guidelines?
- » Do the services develop and teach general skills, such as communicating effectively with supervisors, co-workers, and customers; dressing and conducting oneself appropriately in the workplace; following directions; attending to tasks; solving problems; and general workplace safety and mobility training?

## Community-Based Non-Work

Community-based non-work (CBNW) services support people with disabilities to access community activities in settings where most people do not have disabilities. These services do not involve paid employment.

Activities include general community participation, volunteer experiences, or using community recreation and leisure resources. The majority of an individual's time is spent in the community engaging in activities of their choice. This service category is often referred to as community integration or community participation services.

As the service system continues to advance the goal of full inclusion for adults with disabilities, and to focus on employment in the community, the system must also help adults to access community integrated activities and resources when individuals are not at work.

- » CBNW has been a part of states' developmental disabilities services since the mid-1990s. Since that time, the number of individuals participating in this service and the dollars allocated to this service have grown significantly.
- » Community participation allows people to learn about themselves and what they like to do. These experiences not only contribute to a well-rounded life, but also to career development.
- » CBNW supports can facilitate inclusion and career development in many ways:
  - Assisting the person to engage in community activities, such as turning an interest into a hobby (model railroading, knitting)
  - Participating in religious and charitable organizations and events (a walk to support breast cancer research, volunteering at a food pantry)
  - Building relationships outside work (going to a movie or sporting event)
  - Learning something new (going to an exercise class at the YMCA, taking a class at a craft store)

CBNW services can facilitate a society in which all people are viewed in terms of their abilities, are welcomed into the mainstream of community life,

and have relationships with a range of people.

Community-based non-work services should be developed and implemented using an array of practices. The most important of these are:

- » The supports are individualized and connected to the individual's support plan. This includes supporting the individual to develop and explore employment interests, and also supporting them outside of their work hours. This requires an intensive person-centered planning process.
- » The service system is designed so that service providers are able to be community connectors. Just as integrated employment providers need opportunities to develop community employment networks, service providers need opportunities to identify community resources and develop individualized supports for participation in community life.
- » Individualized schedules are developed that allow for consistent participation in each activity. The schedules are matched to the individual's interests and support needs, not to a provider's schedule. Structure and repetition are needed if people are to gain skills, confidence, and independence.
- » Services are provided to one person at a time, or to a very small group. The ratio of supervision should be between 1:1 and 1:3, with the most personalized ratio of support possible provided.
- » The service provider must organize their business model to support flexible individual services. The business model and organizational structure will need to address individual schedules for each person, assign staff to support each individual, coordinate transportation, and communicate the schedules to individuals, their families/guardians, or residential providers. Implementing a routine yet flexible schedule will help the individual to build comfort and develop relationships with other community members.

### **Here is a simple example of how an individual can receive a mix of personalized activities:**

- » On Monday morning, John, who has intellectual disabilities, visits the library with Mary and Su Lin and receives support from Tony, his Community Connector. In the afternoon John works at his job and receives support from a job coach, Andy.
- » On Tuesday, John volunteers at the food bank for three hours, and is supported by other volunteers. In the afternoon, John works at his job and receives natural supports from a coworker.
- » On Wednesday afternoon, John works at his job and receives natural supports from a coworker. Later in the afternoon, John goes to the gym and participates in a yoga class. He is supported by Tony, who also supports two other individuals who are taking a swimming class at the same time.
- » On Thursday, John goes to the movies and out to lunch with a friend. In the afternoon he goes to the gym on his own. Tony helps him to plan his transportation to the theater and the gym.
- » On Friday morning John is at his apartment and checks in with his job coach, Andy, over Skype. In the afternoon, he works at his job and receives natural supports from a coworker. After work, he goes out for appetizers with a few coworkers. After he gets home, he checks in with his sister over the phone and makes plans with her for the weekend.
- » On Saturday morning, John receives support from his independent living coach with weekly housekeeping activities. On Saturday afternoon, he finishes up housekeeping and relaxes.
- » On Sunday, John meets his sister and her family for brunch. In the afternoon, he does some preparation for his weekly meals and talks with friends over the Internet.

## Quality indicators for community-based non-work services in your state

- » Expectations for individualized CBNW are clearly stated in state policy and provider practices and procedures. These expectations include:
  - Encouraging presence and participation in the community
  - Developing social capital, friendships, and networks
  - Supporting participation in community leadership roles
- » For working-age adults, CBNW is used to build a fully inclusive life. This includes helping individuals develop skills and interests, and supporting them when they are not working.
- » The individual receives services personalized to their interests and needs, decides how they will spend their time, and is provided with the level of support they require.
- » The personalization of services should yield ratios of 1:1 support per individual and no more than 1:3. The person's need for paid support should also be re-evaluated as they gain skills and competencies with each community-based activity.
- » The decision about whether to spend time with other people with developmental disabilities is based on the preferences of the individual—not of a provider or family member.
- » Case management services focus on an intensive person-centered process that begins with the individual's goals and desires, not with the available services. Case management staff supports the team to identify paid supports (e.g., service providers) and natural supports (e.g., family, friends, religious community, co-workers).
- » Transportation is arranged on a personal basis to accommodate the individual's choices throughout their day, and supports a realistic mix of employment, leisure, and overall life activities.



## Resources

### Federal

Centers for Medicare and Medicaid Services. Informational bulletin: *Updates to the §1915(c) Waiver Instructions and Technical Guide regarding employment and employment related services*.  
<http://downloads.cms.gov/cmsgov/archived-downloads/CMCSBulletins/downloads/CIB-9-16-11.pdf>

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U.S. Department of Justice. Statement of the Department of Justice on Enforcement of the Integration Mandate of Title II of the Americans with Disabilities Act and *Olmstead v. L.C.*  
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U.S. Department of Justice. Olmstead enforcement:  
[http://www.ada.gov/olmstead/olmstead\\_enforcement.htm](http://www.ada.gov/olmstead/olmstead_enforcement.htm)

Rehabilitation Services Administration. Definition of integrated setting:  
<http://www2.ed.gov/policy/speced/guid/rsa/tac-06-01.pdf>

### Advocacy

APSE. Map with links to state-specific resources: [www.apse.org/employmentfirst/](http://www.apse.org/employmentfirst/)

The ARC: [www.thearc.org/page.aspx?pid=2369](http://www.thearc.org/page.aspx?pid=2369)

National Council of Self-Advocates of the ARC:  
[www.thearc.org/page.aspx?pid=2660](http://www.thearc.org/page.aspx?pid=2660)

National Youth Leadership Network:  
[www.nyln.org/](http://www.nyln.org/)

Self-advocacy online:  
<http://selfadvocacyonline.org/stories/>

StateData provides state and national data on employment services and outcomes:  
[www.statedata.info](http://www.statedata.info)

### Research

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